

**UNITED STATES DISTRICT COURT
DISTRICT OF MASSACHUSETTS**

DAVID MARSTERS,)
by his next friend, Nancy Pomerleau;)
LORRAINE SIMPSON, by her guardian, Sara Spooner;)
SHERRI CURRIN, by her guardian, Sara Spooner;)
CAROLE CHOJNACKI, by her guardian, Sara Spooner;)
RICHARD CAOUEITE, by his guardian, Sara Spooner;)
DONALD GRANT, by his guardian, Sara Spooner,)
on behalf of themselves)
and other similarly situated persons; and)
MASSACHUSETTS SENIOR ACTION COUNCIL,)

Plaintiffs,

v.

MAURA HEALEY, in her official capacity)
as Governor of the Commonwealth of Massachusetts;)
KATE WALSH, in her official capacity)
as Secretary, Executive Office of Health and)
Human Services;)
MATTHEW GORZKOWICZ, in his official capacity)
as Secretary of the Executive Office of Administration)
and Finance;)
ELIZABETH CHEN, in her official capacity as)
Secretary, Executive Office of Elder Affairs;)
and MICHAEL LEVIN, in his official capacity)
as Assistant Secretary of MassHealth,)

Defendants.

CIVIL ACTION NO.
1:22-cv-11715-PBS

SUPPLEMENTAL AFFIDAVIT OF BARBARA PILARCIK, R.N.

I, Barbara Pilarcik, hereby state as follows:

I. Overview

1. On April 14, 2023, I submitted an Initial Affidavit in conjunction with the Plaintiffs' Motion for Class Certification. In that Affidavit, I set forth my qualifications and experience, and opinions for each of the Individual Plaintiffs with respect to the appropriateness

of transitioning each to the community, their need for residential services to live in an integrated setting in the community, their preferences to leave the nursing facility, their ability to be served in the community with waiver or other supports, the lack of sufficient information provided to them about community options, and, for those with serious mental illness, their unmet needs for specialized services.

2. Despite being qualified to live in the community, three of the Individual Plaintiffs have been rejected by the one residential waiver program created to serve people in nursing facilities without regard to the type of disability they may have – the Moving Forward Program – Residential Services (MFP-RS) waiver. Each was rejected because of general “safety” concerns. I have been asked by the Plaintiffs’ Counsel to review the denial of eligibility for these three individuals and determine if there is any common reason or cause for their continued institutionalization.

3. I have also been asked to review the clinical history of the one Individual Plaintiff who recently left the nursing facility to determine if there is a risk of her being readmitted and re-institutionalized. This Supplemental Affidavit sets forth my findings on these issues.

II. Summary of Clinical Findings

4. In preparing this Supplemental Affidavit, I reviewed the Defendants’ Memorandum, the affidavits of Beth Lucas, Amy Bernstein (including the two volume Addendum), and Melissa Guyer.

A. David Marsters

5. David Marsters is a seventy-three-year-old White male who has resided at Hillcrest Commons nursing facility in Pittsfield, Massachusetts, since October 2016. His most recent applications for the MFP-RS, MFP-CL, ABI-RH, and ABI-N were filed on March 30,

2023. The ABI waivers were denied on June 13, 2023, due to not having a qualifying brain injury. The MFP waivers were denied due to “exhibiting signs of health and safety risks which cannot be managed in any waiver setting.” There were seven health and safety risks checked in the ten item Risk Assessment list, as well as a risk of psychiatric decompensation, a risk for not having his basic needs met due to behaviors, and a risk for exploitation.

6. While it is true that Mr. Marsters engages in certain challenging behaviors, he has consistently and, at times, forcefully stated his desire to return to the community where he lived successfully for many years. The only aggressive incident cited occurred in 2016, nearly seven years ago, prior to which Mr. Marsters lived successfully in the community for over thirty years. He was served by the Carson Center, a community mental health outpatient clinic from 1986 until just prior to the group home placement in 2016 – a period of over thirty years. One failed group home placement led to his institutionalization, beginning a cascade of events that resulted in his placement at the nursing facility and his current state of unhappiness.

7. Mr. Marsters has also suffered from not being diagnosed with Autism Spectrum Disorder (ASD) until October 2020. He is currently in an environment that can be noisy, chaotic, overly stimulating, and restrictive. Disabilities professionals have long documented that this type of environment can be very detrimental to people with sensory deficits, as in autism. Further, Mr. Marsters goes out weekly with an autism specialist from Autism Connections and is cooperative and responsive to the worker. His challenging behaviors represent his distress at his situation and his inability, for these past seven years, to live in a quieter, more structured, and independent setting.

8. In addition, the nursing facility is not implementing any recognized Positive Behavior Intervention Services (PBIS) or crisis prevention program for Mr. Marsters that would

possibly reduce any behavioral issues. Instead, facility staff solely rely upon “re-direction,” or simply telling him to go to his room as the primary method of teaching him to manage his behaviors. There are several services commonly used in community programs and facilities to support individuals with challenging behaviors: Applied Non-Violence, PBIS, Crisis Prevention Intervention, and Quality Behavior Solutions (QBS) Safety-Care. However, none of these recognized methods or similar strategies are listed in his nursing facility Plan of Care or implemented in the facility.

9. The UMass waiver reviewer lists SMI as another reason for the denial of eligibility, yet at least two of Mr. Marsters’ psychiatric diagnoses have been questioned by the nursing facility or his own doctor, in light of the recent ASD diagnosis. During the time that Mr. Marsters was a young child, and throughout his adulthood, the characteristic behaviors of people with autism were often labeled with psychiatric diagnoses. In fact, Mr. Marsters does not display psychotic symptoms, and there are no psychotic symptoms in the records from the nursing facility. Being irritating, demanding, repetitive, yelling, and unkind is not evidence of a psychiatric disease.

10. Another reason listed by the UMass reviewer is sexual behaviors. Mr. Marsters does display some behaviors that should not be occurring in areas or in ways that are visible to others. However, other than documenting these behaviors, it does not appear that anyone is counseling him on appropriate sexual behaviors. His behaviors are not directed toward others, and he would benefit from counseling on how to privately and respectfully enjoy his sexuality, which is generally available in many community programs. Consenting adults should be able to engage in consensual sexual behaviors so long as they do not infringe upon other people’s rights

or spaces. Mr. Marsters, who is a widower, should be helped to understand how to address his sexual needs in a positive, private manner.

11. In his waiver assessment, the nurse checked “Other” as another risk. But this factor is so general that it applies to virtually every person with a significant disability or who is an elder. Many people with various illnesses suffer from decompensation from time to time; that is why community services are so valuable and pharmacological interventions are only one contributory to the person’s ability to maintain mental health. It is also important to note that Mr. Marsters lived successfully until his decompensation episode in 2016. Exploitation of vulnerable people is always a concern, and agencies and nursing facilities take measures to ensure that there are policies and procedures in place to protect people from harm. The state agencies that regulate both nursing facilities and community programs administered by the Department of Developmental Services (DDS) and Department of Mental Health (DMH) are very clear on the requirements of protection from harm.

12. Mr. Marsters requires a structured group home setting which will enable him to successfully re-enter the community. He would benefit from living in a group home where there is clinical expertise regarding autism including behavior plans, staff training, data collection and a psychologist with autism credentials. He would benefit from living with far fewer individuals, as is found in MFP residential homes, and from a structured routine that he enjoys participating in, consisting of activities he is interested in, such as sports and magazines, and an environment where he has privacy and counseling regarding respectful ways to manage his sexuality. He would continue to need psychiatric monitoring and a review of his medications by a psychiatrist with experience in autism. He has been in an institution for the last seven years and needs some

well-established supports, like PBIS, to expand his coping mechanisms and address some of the behaviors he learned in the nursing facility.

13. Mr. Marsters is currently followed by Case Management from DMH and Autism Services from DDS. In a note written on January 3, 2023, the DMH Critical Needs Case Manager states that his role is “to find alternate placement.” In the same note, the head of social work at Hillcrest Commons states that Mr. Marsters can be redirected. DDS, in a note written on January 13, 2023, states that he would do well in a group living situation. Those who know him best, his sister (who also serves as his health care proxy), case manager, and social worker all say that he would benefit from living in a group home. The UMass clinical reviewer ignores most of these opinions and never even spoke with Mr. Marsters’ sister, instead placing greater weight on an incident from 2016 and his outdated psychiatric diagnoses, rather than current information and the distinct possibility that much of his challenging behavior comes from his deep unhappiness at his restrictive, noisy, unstructured, and unwanted living situation.

14. Pathlight, the agency I directed for several years, operates several homes and a day program that were designated for behaviorally intense individuals in addition to the Regional Autism Center. Mr. Marsters is very similar to several of the individuals in our homes in the Franklin County area who require support but live active lives in the community. Some of these individuals with similar or even greater needs had one-to-one staffing during awake hours. We employed a psychologist with autism credentials and had detailed behavior plans to enable the individuals to develop appropriate behaviors and effective responses to stressful situations. We had extensive staff training, and collected and analyzed data that enabled the psychologist to determine whether or not the behavior plan was working and whether staff required additional training. We found that the consistent application of the behavior program by trained staff,

monitored and evaluated by a clinical psychologist, enabled all the people we served to reduce or eliminate their behavior- related incidents, such as physical and verbal aggression, throwing objects, threatening staff and others, running away in the community and property destruction. We implemented a program to help manage challenging behaviors entitled “QBS Safety-Care,” developed by Dr. David Lennox and used throughout the United States and Canada. The program provides skills and competencies to prevent, minimize and manage behaviors with dignity, safety, and the possibility of change. It is based on technologies from Applied Behavioral Analysis and PBIS and is a re-enforcement-based approach to developing new skills and maintaining safety.

15. PBIS is required by DDS of all its providers, including providers serving individuals in the MFP-RS waiver, and is routinely implemented in DDS provider agencies. QBS Safety-Care builds upon PBIS and provides additional methods to help individuals with challenging behaviors. With clinically written and effectively implemented behavior support plans, PBIS as a foundation for all staff interactions, and QBS Safety-Care for crisis management, community providers ensure that the individuals served in group homes have the opportunity to grow and change negative behavior. I have seen over and over people improve under these services and become happier and more content with their lives, once their negative behavior is replaced with socially accepted behaviors. As an individual with autism, Mr. Marsters would benefit from this approach.

16. I am familiar with agencies other than Pathlight that operate programs for people with needs similar to Mr. Marsters such as Berkshire Family and Individual Resources, the Berkshire County Arc, Guidewire, Service Net, the Center for Human Development and

Behavioral Health Network, all in western Massachusetts. It is my understanding that many of these providers serve people with similar needs and conditions to Mr. Marsters.

17. In my view, the restrictive eligibility criteria used to exclude Mr. Marsters from the MFP residential waiver program can and should be modified to align with other community waiver programs operated by the Executive Office of Health and Human Services (EOHHS). DDS has found Mr. Marsters eligible for Autism services, which by design do not include residential services, and DMH has found Mr. Marsters eligible for its services and are actively looking for a group home placement.

B. Richard Caouette

18. Richard Caouette is a sixty-four-year-old White male who has resided at Bear Mountain at Worcester since June 30, 2020. He applied for a MFP-RS waiver on March 17, 2023, and it was denied on May 12, 2023. He also has a pending application for the MFP-RS waiver, filed on July 11, 2023. His prior denial was due to health and safety concerns. The UMass reviewer stated that he is psychiatrically fragile after multiple medication adjustments. The clinical assessment was conducted on March 20, 2023, and states that he does not have dementia or an acquired brain injury. It lists several psychiatric events, and states that once he is stable, he should re-apply for the waiver. As noted above, he has.

19. Of note, the DMH Pre-Admission Screening and Resident Review (PASRR) of August 2, 2022, states that Mr. Caouette does not meet the criteria for Serious Mental Illness. In the Summary, the PASRR reviewer states that while Mr. Caouette has mental health diagnoses and functional impacts on major life activities related to his mental health diagnoses, he has not had any mental health treatment more intensive than outpatient treatment in the past two years. Apparently, the PASRR reviewer does not consider inpatient nursing facility placement for

psychiatric reasons, where Mr. Caouette receives numerous psychiatric medications, to be “more intensive than outpatient treatment.” Hence, based on all available information and federal criteria, the PASRR reviewer determined SMI cannot be confirmed based only on documentation. Two reviewers, assessing him approximately six months apart, came to opposing conclusions regarding his mental health status. This leaves him too mentally ill for the MFP waiver program, but not mentally ill enough for DMH eligibility and specialized services.

20. Mr. Caouette can be safely served in the community, through a MFP waiver residential setting, with appropriate staffing, medication monitoring, and monitoring for physical health concerns. He should be followed by a psychiatrist and have his medications evaluated once he has adjusted to the quieter, less restrictive and more personalized environment of a community residential setting.

21. Mr. Caouette would also benefit from the approach we used at Pathlight, as described in the information above for Mr. Marsters. QBS Safety-Care can be used for people with challenging behaviors whether or not they have autism. It is currently used in human service agencies, schools, and nursing facilities. We used QBS Safety-Care for individuals who engaged in property destruction and were able to eliminate that behavior and replace it with a more effective approach to managing their emotional dysregulation.

22. Mr. Caouette is very similar to individuals served by Pathlight. If Mr. Caouette does have dementia, his needs could be met in the community, as we served people who had dementia, even including people on hospice. It is my expert opinion that given the progress Mr. Caouette has made in the last year, his similarities to other individuals served in the community, his fervent desire to leave the nursing facility, and the types of supports available through the MFP-RS waiver, he should be approved for the MFP-RS waiver application now pending.

C. Donald Grant

23. Donald Grant is a sixty-four-year-old White male who has resided at Worcester Rehabilitation and Health Center since May 29, 2021. He applied for MFP-RS and ABI-RH on September 1, 2021. He was denied eligibility on January 10, 2022. The clinical eligibility assessment states that he meets the criteria for an acquired brain injury, based upon a medical diagnosis dated January 12, 2018. He was denied eligibility for both waivers due to health and safety concerns, and requiring twenty-four-hour care that cannot be safely provided in existing community programs. The reviewer cited several behaviors that indicate placing himself in harmful situations.

24. Mr. Grant has several psychiatric diagnoses which he denies. He has a diagnosis of personality disorder, which requires a mental health provider who is trained and certified in treatment specific to these types of conditions. At minimum, he should have a comprehensive psychiatric and behavioral assessment by a specialist in this field to determine if there is counseling that would help him resolve some of his challenging behaviors. He is morbidly obese, and his weight is causing additional health concerns, such as being bed-ridden. He also needs services from a medical program that has expertise in helping morbidly obese individuals lose weight. With new pharmacological treatments now available, Mr. Grant should be assisted in addressing this serious health concern. He does not receive any treatment while at the nursing facility for either of these conditions.

25. It is my expert opinion that these two problems can and must be addressed to allow him to resume a life in the community. He desperately wants to leave the restrictive environment of the nursing facility, yet engages in behaviors that can alienate the very people who could help him leave. The longer he stays at the facility, the angrier he has become and the

harder it is for him to change his behavior. He resists a mental health diagnosis, as do many people who are labeled with personality disorders. He had a PASRR evaluation on November 30, 2022, which states that he does have a SMI, and recommends individual psychotherapy, case consultation, psychotherapy for crisis, a behaviorally-based treatment program, medication evaluation and monitoring, and stress and social counseling. His PASRR evaluation also recommends that he be referred for MFP waiver services, as well as other DMH residential programs.

26. A DMH case manager made an initial visit on January 4, 2023, conducted a Critical Needs Assessment on January 12, 2023, and developed an Individual Service Plan on January 12, 2023. His first priority “Need Area” is housing. The DMH case manager visits him more than weekly, and each time he notes that Mr. Grant wants to leave the nursing facility and maintains that he does not have a mental health diagnosis. However, the case manager is developing a rapport with him, and they discuss family situations and what he would like to accomplish. On March 3, 2023, the case manager also proposed a DMH group living program on Massasoit Road (town not documented), demonstrating that a DMH staff person believes Mr. Grant can be safely and appropriately served in the community.

27. It is my expert opinion that Mr. Grant can be safely served in the community if he is provided with counseling specific to his needs and if he is provided with bariatric services that help him address his obesity. We now know that obesity is not a choice, but a disease, and there are effective treatments, including new pharmacological treatments, that can help people with this difficult challenge. Mr. Grant does not want to remain in the nursing facility, but he needs specific clinical support that will help him address his challenging behaviors to be successful living in the community. He needs a specialized program of behavioral support and coordination

with other physical health specialists as indicated by his medical diagnoses. He needs a clinician with expertise in treating personality disorders. He is not receiving any behavioral support or programming while in the nursing facility or help with managing his physical disabilities.

28. The agency I directed for many years has served individuals with similar or greater needs and risks. There are mental health agencies in central and eastern Massachusetts that serve individuals with needs similar to Mr. Grant. His DMH case manager identified one such program as a possible community residence. Mr. Grant's unwanted institutionalization has created a downward spiral of hopelessness, leading to negative behaviors, which leads to denial of services and the spiral continues. At this point, he cannot stop the spiral by himself, but needs expert clinical help. He is motivated to leave the nursing facility and was able to live successfully in the community for many years. Now he needs the support of the waiver system to re-enter the life he once had.

D. Carole Chojnacki

29. Carole Chojnacki is a sixty-seven-year-old White female who had resided at Rehabilitation and Nursing Center of Everett until on or about May 1, 2023. Before her admission to the nursing facility, she lived for many years in a community home, but was transferred to a nursing facility because she stopped taking medications and decompensated. She was accepted into the MFP-RS waiver in 2023, but the community residential provider refused to serve her because she indicated she would not participate in therapy. Although she appears to be stable and thriving in her new DMH community home, based upon her prior clinical history, there remains a serious risk of re-institutionalization in a nursing facility, due to her longstanding pattern of periodically not taking her medications and then decompensating.

30. Individuals with psychiatric conditions like schizophrenia do not always comply with medication treatment, often due to lack of insight and intense side effects of medication, leading to the recurrence of symptoms and decompensation. DMH's "Assessment of Service Needs" for Ms. Chojnacki, dated January 30, 2023, lists over twenty psychiatric hospitalizations in the past decade, documenting the serious and ongoing risk of re-institutionalization for Ms. Chojnacki. The PASRR of October 26, 2022 confirms this risk, as did the PASRR of October 12, 2021. In my interview with her guardian in March 2023, Ms. Mayes noted that Ms. Chojnacki repeatedly has been placed at serious or even imminent risk of institutionalization, due to poor hygiene, poor eating, and poor housekeeping. Ms. Mayes further stated that this is a cycle that happens due to lack of support and has been true for at least the last three or four years. She described Ms. Chojnacki as needing trained staff who will recognize the signs of decompensation and respond promptly, including consistent medication monitoring. It is critically important that Ms. Chojnacki has services that are capable of responding at the first signs and symptoms of non-compliance and/or change in her psychiatric condition. Otherwise, Ms. Chojnacki will continue to cycle in and out of nursing facilities and endure months of needless suffering.

III. Conclusion

31. In my view, the restrictive eligibility criteria used to exclude David Marsters, Richard Caouette, and Donald Grant from the MFP residential waiver program can and should be modified to align with other home- and community-based residential services and residential waiver programs operated by EOHHS.

Signed under the pains and penalties of perjury this 20th day of August, 2023.


Barbara Pilarcik, R.N.